

A PHENOMENOLOGICAL APPROACH TO UNDERSTANDING THE
MEANING OF ADJUSTMENT TO CHRONIC PAIN

By

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ABSTRACT

This study investigated the meaning of adjustment to chronic pain.

Three co-researchers were interviewed in intensive sessions. They were asked to describe the story of their adjustment to chronic pain. The interviews were tape-recorded, transcribed as "protocols", and formed the data base for the study.

The meaning of adjustment to chronic pain was discovered through a phenomenological methodology. The protocol analysis yielded the themes, the comprehensive phenomenological description of adjustment to chronic pain, and the essential structure.

Implications for further thinking and for practice were presented.

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CHAPTER 1

Introduction

Chronic pain syndrome is a disabling condition in which the experience of pain continues over six months past the precipitating event. Much has been written from a treater's point of view, yet I have discovered no attempts to understand and describe the experience of chronic pain from the experiencer's perspective. The costs to insurance systems has been documented (Richards *et al.*, 1980), but the costs in terms of human experience have not been presented. Nothing has been written about the way in which adjustment to chronic pain is experienced by people. Trieschmann (1980) expressed the dangers inherent in applying theory to experience without first identifying and describing the experience. People feel victimized by professionals who write articles based more on theory than reality. She gives a very good example of the bind caused by adherence to assumptions without reality checking: "Have professionals, in clinical interactions, placed disabled persons in a 'catch 22' position? If you have a disability, you must have psychological problems; if you state that you have no psychological problems, then this is denial and that is a psychological problem." (p. 46)

This study has addressed the question: What is the meaning of adjustment to chronic pain? The work came into being for several reasons. First, I wished to address the neglected area concerning people's actual experience of adjustment to chronic pain. I believe that human experiencing is valuable content for research, and that clear understanding, identification and description of the phenomenon of human experience must be the important first step of theory building. Since human experience is a part of the world we perceive, understanding experience has implications for how we lead our lives. (Further discussion on the philosophical basis for this study will be presented in Chapter Three.)

I also had personal reasons, coming from my own experience, for embarking on this project. I have worked for two years in a behavioral medicine clinic, in a self management program, with people challenged with chronic pain. In working with groups of clients, I found that people's sharing of their experiences was a potent force for inspiration, clarification and change within the group. Their descriptions of how they had been involved in their adjustment process had impact on other group members, including myself. I resolved to describe, make visible, and validate this experience in hopes of offering assistance, direction and inspiration for others. I have also had my own experience with accidents, pain and involvement with an insurance system, so that in some ways I

have been "on both sides" of this experience.

Since I wished to investigate human experience, and in particular the experience of adjustment to chronic pain, I chose a phenomenological methodology, based on Colaizzi's (1978) model. I sought to identify and describe the experience of adjustment to chronic pain through working with three co-researchers in intensive interviews. The theoretical framework will be discussed thoroughly in Chapter Three of this thesis.

In accordance with the phenomenological approach, I worked to make explicit my assumptions about adjustment to chronic pain. Although I realized that I could not make my assumptions disappear, I believed that by articulating what they were, I could work to suspend their operation so that I could be more fully present to the phenomenon. I believed, at the outset, that adjustment was not something which was conferred upon an individual, it could not be consumed as an end product; rather, adjustment implied continual change and growth based on responding to daily experience. I believed that, in adjustment to chronic pain, self-esteem was important, and that people had to have a sense of being worthwhile and productive. They must find ways of experiencing in the world, from which to derive a sense of value. Since they could not work in the same manner as before their injury, they needed to reduce the emphasis on physical productivity, and to use other talents. Support from others was extremely important, and set the stage for increased self-awareness, attention to personal process and responsibility-taking, all of which I assumed were fundamental to adjustment to chronic pain. I believed that through coming to terms with the experience of chronic pain, people had grown in strength. I considered them to be "survivors".

In Chapter Two, a review of the literature on adjustment to disability, making clear the rôle of assumptions in theory presentation, will be outlined. Chapter Three presents the methodological framework of this study. Chapter Four includes a statement concerning the effect of the study on the researchers. It presents the themes which emerged from the analysis of the data, as well as the phenomenological description and the essential structure of adjustment to chronic pain. The fifth chapter presents the discussion concerning implications for further thinking, for others with chronic pain, for practice, and for further research.

CHAPTER 2

Literature Review

In my review of the literature pertaining to adjustment to disability in general, I have chosen several models which ring true with my experience of the adjustment process of chronic pain patients, and which are congruent with the hypotheses emerging from my experience. I resolved particularly to uncover any stages, steps, or variables suggested in the literature as prerequisite to successful adjustment; to state the assumptions concerning successful adjustment; and then to compare these findings with the findings arrived at with my co-researchers.

My own hypothesis concerning adjustment centres on the conceptualization of adjustment as a process, rather than a fixed state of being which, once reached, is a *fait accompli*; adjustment for me is a multi-dimensional concept which has impact upon all the areas of the experiencing of the individual, and concerns meeting the demands of daily living in an effective manner. With these thoughts concerning adjustment, I was encouraged to answer the question: What is the meaning of adjustment to chronic pain?

Roessler and Bolton (1978) reviewed several definitions of adjustment, especially that of Lazarus (1969) who included as one of the constituents of adjustment "man's efforts, successful and unsuccessful, to deal with life in the face of environmental demands, internal pressures, and human potentials." (p. x) Lazarus (1969) also stated that adjustment could be seen as achievement oriented (having a fixed accomplishable goal) or process oriented (reflective of people's ability to cope with daily stressors). Roessler and Bolton (1978) outlined some of the problems associated with conceiving adjustment as a finite goal state; although there exist no clearly defined steps to achieve adjustment, this conceptualization suggests that all problems are solvable. This can result in individuals assuming that adjustment is a final state without difficulties, and they can be led to make unrealistic expectations concerning their achievements. Roessler and Bolton (1978) distinguished adjustment as a process which is founded upon the realistic belief that experiencing will generate ongoing problems and stresses which necessitate emotional adjustment. Adjustment is the measure to which an individual copes with and resolves the problems inherent in the situational series of daily existence.

Another view of adjustment has been provided by Wright (1983) who has stated that adjustment is based on acceptance of a disability as nondevaluating. This acceptance

facilitates behaviour and experiencing which emerge from a person's own individual assets and traits, as opposed to complying with a normal standard. Wright (1983) discussed the idolizing of normal standards in which normality is perceived as the way to have needs met, and normal standards for behaviour are rigidly adhered to as the fixed marker of acceptability and appropriateness. According to Wright (1983), adjustment is closely linked with feelings of self-esteem, and valuing one's abilities and characteristics; an individual's ability to cope with the existential process of living is based on the beliefs the person holds about the self, and the value with which the self is construed. Adjustment, according to Wright, is a learning process which is based on value change.

Stubbins (1977) has also discussed the relationship between the adjustment process and self-concept; he equated the coping/managing process with a strong, defined self-concept, the ability to deal with ambiguity, and having personal values.

Trieschmann (1980) cited the definition of adjustment provided in Random House Dictionary: "harmony achieved by modification or alteration of a position." (p. 20) She also corroborated the view of adjustment as a process which aims at harmonizing with the environment, and which is continuous throughout the lifetime: "There is no definable end point that can be labelled as 'rehabilitated' or adjusted because, as with all people in all areas of life, disabled persons are continually learning to adapt to their environment in, hopefully, more functional and satisfying ways." (p. 20)

Although several stage theories concerning adjustment to disability have been postulated (Wright, 1983; Fink, 1967; Bray, 1978; see Table 1 for summary), the existence of such stages has been refuted in other places (Trieschmann, 1980; Vargo, 1983; Cook, 1976). It is my purpose to outline, from various authors, further assumptions which are consistent with my experience.

Trieschmann (1980) in an extensive review of the literature, found that descriptions of stages of adjustment are not necessarily applicable to real experience. She cited Dunn's (1969) work, which was a partial test of the stage theory of adjustment to spinal cord injury in particular. The result of this study was a significant variability among subjects, none of Dunn's hypotheses of change were borne out in the data, and Trieschmann (1980) gave commendation of the study as an "attempt to document a theory that has been accepted as true without question." (p. 47).

Vargo, in her 1983 study on adaptation to disability by the wives of spinal cord injured males, looked for evidence of a stage process of adaptation. With specific reference

TABLE I Stages of Adjustment to Physical Disability

Wright (1983)

- I. Denial
- II. Mourning
 - A. Hostility
 - B. Depression
- III. Adjustment
 - A. Enlarging the scope of values
 - B. Subordination of physique
 - C. Containing the effects of the disability
 - D. Transforming values

Fink (1967)

- I. Shock
 - A. Panic
 - B. Anxiety
 - C. Helplessness
- II. Defensive retreat
 - A. Indifference/euphoria
 - B. Low anxiety
- III. Acknowledgement
 - A. Depression
 - B. Mourning
 - C. High anxiety
- IV. Adaptation
 - A. Reorganizing valuing system
 - B. Lowering of anxiety

Bray (1978)

- I. Anxiety
 - A. Fear
 - B. Denial
 - C. Bargaining
 - D. Depression
- II. Accomodation
 - A. Mourning
 - B. Resignation
 - C. Compromise
- III. Assimilation
 - A. Reconstruction
 - B. Integration
 - C. Acceptance
- IV. Reflux
 - Return to any former state

Table I

to the model set out by Bray (anxiety, accommodation, assimilation; Bray, 1978), she discovered that the women in her study did not react as specified by Bray in the anxiety stage. Neither, in the accommodation phase, did the women fit within the prescribed time frame. The assimilation stage, comparable to Maslow's concept of self-actualization, was not found to be realized by the women. Vargo (1983) pointed out that the value of a theory or model resides in its usefulness in illuminating outcomes, and states that: "Examination of (Bray's) model and its applicability to the women in this study has demonstrated that, except as a very rough guide, there is little congruence between (his) findings and those of the present study." (p. 91). She attributed this incongruence to several possible factors, not the least of which is the possibility that reactions have been attributed to subjects which did not emerge from their own experiencing. Cook (1976) stated that the sequential reactions suggested by stage theories are more significantly reflective of the assumptions and beliefs of helpers than the actual experiencing of the clients. Trieschmann (1980) also noted that members of her consumer advisory panel, themselves with the disability of spinal cord injury, have felt "victimized by professionals who write articles about the reactions to disability that are based more on theory than fact." (p. xii) She also suggested the way in which authors have stamped the stages of adjustment from the metal of **their** experiencing, rather than that of their clients/subjects: "It is important to note that each of the preceding descriptions of stages of adjustment is based on the **clinical impressions of the particular author, and that no data have been presented in any of these articles to document the existence, sequence, or duration of these stages.**" (p. 45-6) [emphasis is hers] Trieschmann has asked potent questions of people who would align themselves with theories:

Have professionals seen more distress and psychological difficulty than actually is present? Have professionals **uncritically** applied terms and theoretical concepts from the field of 'mental illness' to describe the 'normal' reaction to an abnormal situation Have professionals been describing phenomena that do not exist? (p. 46).

Cook (1976), Trieschmann (1980) and Vargo (1983) have all emphasized the difficulties with theories which strive to depict the sequential stages of human functioning, most importantly that such theories create a complex of expectations through which we then perceive a particular version of reality; this version of reality is superimposed on individuals even though it bears little relation to **their own** unique experiencing, and can serve to coerce people into patterns of behaviour.

Although the stage theories of adjustment have been refuted, and the dangers of rigid adherence to such theories have been outlined, there are nonetheless several

assumptions about successful adjustment which are worthy of discussion. From my own experience working with people with the disability of chronic pain, individually and in groups, I have generated a list of assumptions which have seemed to be important in successful adaptation. These can be summarized as follows: regard for the self, and belief that the individual is worthwhile, although not the same as before the injury; support from others which is nurturing; the ability to find new ways of accomplishing things, or discovering new pursuits/approaches/ways of living from which to derive value; not placing as much emphasis on physical productivity; increased self-awareness, attention to personal process, and responsibility-taking; the length of the "treatment" process; the ability to deal with despair, frustration, disappointment, fear, anger, and the unknown.

I have found Wright's (1983) work on adjustment to be particularly helpful, especially her conceptualization of adjustment as a learning process based on value changes which help to create conditions facilitative of the acceptance of disability as nondevaluing. She has outlined these value changes as follows (1983, p. 163):

- (1) enlarging the scope of values.
 - (2) subordinating physique relative to other values.
 - (3) containing disability effects.
 - (4) transforming comparative-status values into asset values.
- (1) This value change is based on the appreciation that values exist besides the ones perceived to be lost, and facilitates coming to terms with the loss. This shift involves the realization that the disability is not the only thing that matters; values that a person feels s/he has lost can be seen in a different manner. The scope of values can also expand through a person discovering values which had not previously held importance in the belief system.
 - (2) A person with a disability will be less troubled when s/he perceives physique and physical performance in relative terms, and not as the most important value in the belief system. When a very high value is placed on physical normality and physical achievement, then the individual will feel degraded. Idolizing performance leads to repeated failures, and concomitant feelings of inferiority, shame and depression. Personal evaluation increases as physical performance is seen as a less important measurement than effort and a sense of perspective. Wright (1983) cautioned that

physique, physical performance and especially physical health are important, yet for the chronically ill or disabled not to suffer devaluation in the face of this emphasis, then the other value changes need to take place so that good health can be seen as an asset rather than a comparative-status value.

- (3) It is important to note Wright's distinction between a disabled, handicapped person, and a person with a disability. The use of terminological shortcuts like "the disabled" fosters the spread of this label to the total person. The resulting distortion does not allow recognition of the person's abilities. Wright emphasized the use of expressions which separate status characteristics (such as physique), so that disability on one scale does not escalate into total inferiority. Containing this spread effect applies to both the individual, and to evaluators, so that both groups refrain from perceiving physical or performance disabilities as the focus of a person's personality and behaviour.
- (4) Comparative values suggest how things "should be": evaluation is predicated upon comparison with a standard. Asset valuing, on the other hand, suggests that evaluation be based on "what is", inherent qualities and current attributes, rather than on comparison with an external standard. The imposition of comparative values has the result of a person falling short of a standard, and feeling degraded by this discrepancy. "It is not what you have lost, but what you have left that counts." (Wright, 1983, p. 183).

Roessler and Bolton (1978) have similarly put forward ideas which have seemed useful when considered in relation to my work with chronic pain patients, and the adjustment process they are involved in. They summarize the positive striving model of adjustment which includes the following: a) positive self-regard and truthful self-awareness, b) a tendency to self-actualize, c) an integration of aspects of the personality, d) perceiving reality in an accurate manner, e) a relative freedom from perceptual distortion, f) autonomy, g) environmental mastery in terms of love, work, and play in interpersonal relations and h) efficiency in problem solving. Sechrest and Wallace (1967) have pointed out that this model is useful in that it is process oriented, and deals with a large variance of behaviour. Difficulties arise from the value judgements implicit in the concepts, and the difficulties in measuring self-actualization, positive regard, and so on.

Roessler and Bolton (1978) went on to postulate their own "behavioral coping" model of adjustment in which maladjustment is conceptualized as problems in living, and treatment is targeted toward assisting clients to identify situational problems and learn positive responses to these problems. The behavioral coping model focuses on managing the environment in an efficient manner in order to maximize positive rewards and minimize pain and punishment.

Although Bray's (1978) sequential stage model of adjustment has been refuted (Vargo, 1983), the meanings underlying his concept of assimilation as the ultimate phase of adjustment have implications for people dealing with chronic pain. He sees this stage as a time for an individual to develop a way of being in the world, and then to interact with society at large. Growth, challenge, and change mark the experience of this period, which progresses through the three phases of reconstruction, integration, and acceptance. During reconstruction, people reflect on themselves, identify areas for change, examine their relationship to the world, and explore ways in which to derive meaning from their experiencing. Integration emerges from the momentum of personal evaluation. In this phase, people identify goals, develop strategies to attain these goals, and implement plans of action. People are constructing their lives through drawing on their resources. They initiate relationships with others. This culminates in the final phase of acceptance which Bray likens to Maslow's concept of self-actualization, in which people appreciate their worth.

Fink's (1967) four-part model of adjustment resolves in the adaptation phase, the period during which people actively and constructively cope with their situations. Fink pictures this period as a culmination of the reorganization required to cope. People develop a sense of value based on their personal qualities; they realize that although they are not the same as they were previously, they still have valuable contributions to make. People explore their resources, and experiment with action; this leads to satisfaction, and they look to the future. People can begin to see their crises as positive ways to more profound understanding of the meaning of life, and as strengthening preparation for the future.

The medical model of adjustment to disability has had significant impact on people with chronic pain. Roessler and Bolton (1978), in their review of models of adjustment, set forth the assumptions implicit in the medical model as they perceive them. This model assumes that maladjustment stems from some underlying cause, but does not explicate what constitutes adjustment. The medical model has limitations in that pathology, or the cause of the absence of adjustment, is not easily identified or measured. Adjustment is seen as a goal state reached when the underlying pathology has been "treated", a state not affected

by environmental, cultural or psychosocial forces. In my thinking about the medical model, as related to adjustment to chronic pain, I have noted that it seems to operate on the following assumptions:

- if the pain (or pathology) is not treated successfully (since there is the belief that everything can be treated with this model), if the pain does not go away, then the burden of responsibility is placed on the patients with the thought "it's all in their heads".
- medication and surgery are ways to get rid of the pain.
- the practitioners of the medical model believe they are "right" and the patients are "wrong".
- people are not treated as a whole person; they are divided into parts. People are referred to as "low backs" and "necks". This mind-set can lead to an impatience with "the whole person", who is a feeling, thinking being living in a family system in a particular societal and cultural context.

In Chapter Four, the experience of my co-researchers with the medical model will be presented.

LeShan's (1977) work with cancer patients, who often experience long-standing, debilitating pain, has implications for people dealing with chronic pain. He examined many of the assumptions of traditional helping, and set forth hypotheses, from his experience with crisis therapy, concerning adjustment to chronic pain and illness.

LeShan believes that self-esteem is essential, and that with increasing self-esteem, change is possible; people can begin to view life in a more positive and hopeful light. LeShan reviews the negative aspects of the assumptions inherent in traditional psychotherapy. He has found it difficult to discover remarks about positive psychological forces; in the traditional approach, positive behaviour was labelled as sublimation and over-compensation, and the positive forces giving rise to these actions, as illusions, or reactions against negative impulses. LeShan suggests that this view has undermined the belief in the trustworthiness of individual people and their experiencing. People's reporting is seen as untrustworthy, and the right to be believed is eroded. LeShan rejects this viewpoint. His assumption is that pathological drives result from frustration when people are unable to fulfill themselves in their own ways; he believes that people are basically

motivated in a positive direction to achieve their potential.

LeShan states his belief that people cannot see themselves in a positive manner unless the helper also subscribes to this view. He discusses the importance of real interest, careful attention, and belief in the client's report of experiencing. Healing is facilitated by the therapist helping people to function in their own ways as fully as possible, by asking not "What is wrong with you?", but "What is right with you?"; "What are your special ways of being, relating, acting, creating?" (LeShan, 1977, p. 110).

The problems resulting from the assumptions made by professionals, the tremendously individual and variable process of adjustment, the lack of clear-cut stages of adaptation, and the imposition of inappropriate frameworks to "interpret" people's experience, have all been noted. The co-researchers speak for themselves concerning the meaning of adjustment to chronic pain; a thorough description of the results, theme constituents, phenomenological description, and essential structure, are presented in Chapter Four. In the next chapter, the methodology used in this study is outlined.

CHAPTER 3

Methodology

The Phenomenological Approach

Phenomenology, according to Colaizzi (1978), has as its basis the belief that experience is legitimate psychological content. The development of psychological investigation of experience has meant redefining "objectivity". Traditionally, objectivity has meant separation from human experience: "objectivity resides wherever experience is not." (Colaizzi, 1978, p. 51). Colaizzi (1978) defines objectivity to be "fidelity to phenomenon" (p. 52); one's statements reflect an accurate, precise, responsible adherence to the reality of the phenomenon that one is experiencing. Objectivity is careful attending to the information the phenomenon provides, not a labelling of what the phenomenon is.

Colaizzi (1978) summarizes the concept of "experience" from a phenomenologist's point of view:

- (1) Experience is objectively real.
- (2) Experience is not an internal event, but is a presence in the world.
- (3) The world presence of experience is existentially significant.
- (4) Experience is legitimate and important content for understanding human psychology.

The methodology for the objective investigation of human experience must start with the experience itself. The investigation must remain true to the experience, and refrain from construing, controlling, denying, or changing it. Descriptive methods are evoked by each psychological phenomenon itself; the way in which we approach an enterprise or project, our assumptions and the meanings we place implicitly in the project, influence our engagement in the enterprise. In research projects, the end value as conceptualized by the researcher will affect how the person will proceed with the project.

The phenomenologist explores the relationships amongst content, method, and approach. (Giorgi, 1970). In thinking about this study, I commenced by reflecting on the reasons I was involved with this phenomenon in the first place, and to bring into

awareness my own assumptions and predispositions which affect my approach. Completely bias-free research is never possible; in fact, it is my very interest and biases which motivate me to complete this study. I must, however, work to explicate what my assumptions are so that I am freer to attend to the phenomenon. The understanding of the phenomenon to be researched is reason for the research to go forward; this understanding is in true contact with the phenomenon, and not in control of it. The resulting awareness can be actively applied in the world of which human experiencing is a co-constituting part. To begin, I must start with the description and identification of the phenomenon; in order to identify the psychological phenomenon of adjustment to chronic pain, I commence to describe the phenomenon as people perceive it, thereby working with them to create the meaning of this experience.

The nature of dialogal research means that the research takes place between co-researchers (Friere, 1970), without the demarcations imposed by professional titles, or subject/researcher status. Contact is between persons both working to make clear the meaning of experience. Trust is an integral part of dialogal research, since co-researchers engage in disclosure of assumptions during the dialogue. The conditions of their lives are brought into focus, and again trust is an important prerequisite. Dialogal research leads to existential insight, and, as Colaizzi (1978) believes, therapy. My experience gave support to this belief; time was taken at the end of each session to share the actual experiencing of co-researching, the many thoughts and feelings engendered by our participation in dialogue together. Human research as a type of existential therapy seeks to illuminate the wholeness of the human situation as it is experienced. All of the co-researchers commented on the usefulness of the experience, with statements such as "This was good for me."

Description of Co-researchers

The rationale for dialoguing intensely with people rests in my belief that people are the experts; they are the centres of their experiencing. When I began to think about the meaning of adjustment to chronic pain, I realized that my assumptions about adjustment would be operating as I chose my co-researchers. I chose people who were working, not on regular analgesic medication, and whose self-reports were that they had their lives "back on track". I also chose people who were able to describe their experience. All my co-researchers were involved in industrial accidents, and therefore, involved with the Workers' Compensation Board; they were all challenged with chronic pain for five, twelve, and twenty-three years; they had all completed the self-management program in which I

work. I knew them all, and had worked with them over a period of several months. I had first intended to interview six people, but after I interviewed three people for two and three hour sessions, I found a commonality of experience, and a magnitude of information which surprised me. I experienced a sense of the totality of the phenomenon, and when seeking validation from my co-researchers, they were unanimous in supporting the thorough representation of the experience in the phenomenological description.

One male co-researcher is a government enforcement worker; he returned to his pre-accident employment. One female co-researcher is a hospital worker; she, too, returned to her previous work. The third co-researcher, also female, was working in the hospitality industry at the time of her injury; she has since changed to working with people in a helping context.

The Dialogal Sessions

I began to think about the interviews, and the need to understand the phenomenon as people experience it. I generated a list of questions which I then examined to discover my own preoccupations which were embedded in the questions. I worked with the idea of creating questions which were neither leading, nor studded with biases. More and more I realized that my job was to facilitate the telling of the story, the description and illumination of the phenomenon, and I abandoned my question format. I believed that the story would unfold, with attentive, evocative listening, and trust. I developed the basis for an introductory statement which provided the canvas and materials for people to begin to paint a picture of their experiencing: people come to terms with pain in many ways, and I would like to hear the story of the beginning of your pain, what happened over the period of time, and how you got to the point where you are now, which is the end of the story.

My rôle, as I found it, was to provide reflection and paraphrasing so that the description of the experience became deeper, more vivid and detailed. I sometimes asked direct questions in order to better understand an event, or a feeling. I asked each co-researcher one standard question: If you had the opportunity to speak with others dealing with chronic pain, what would you say to them? I was prepared to encourage clarification of the colours of the painting the co-researchers were creating as they tapped their own experiencing.

The sessions were two and three hours long (two–two hour, one–three hour), and were taperecorded. (These sessions were transcribed, and formed the basis, as protocols, for the analysis of the experience.) After the co-researching interview, I spent time discussing with my co-researchers the feelings that had emerged, how they found the process, and how they felt after doing the dialoguing. This phase of the interview was important because many intense feelings and thoughts came up during the process.

Analysis and Interpretation

The data, in the form of the protocols (the transcripts of the interviews), was interpreted phenomenologically using the methods set out by Colaizzi (1978). I first read, and re-read, the protocols to gain a sense of their meaning, and to familiarize myself with all the facets of the description of the phenomenon.

I then took from the protocols significant statements which directly dealt with the experience of chronic pain. Meanings were then formulated from the significant statements. This process involved springing from the original data, and arriving, through insight, at what the co-researchers *mean* by what they say. The goal was to illuminate meaning which was there, and not to deposit meaning upon the statements. Each protocol was analyzed in this manner.

The next step was to organize the formulated meanings into clusters of themes, allowing themes common to all subjects to emerge. Again, the themes had to be related to the meanings, and to grow from them, not be imposed on them. I also included themes that were not suggested by all co-researchers' protocols. The rationale for this practice was described by Collier and Kuiken (1977) when they discussed the importance of including material, since lack of articulateness, different areas of attention, or lapses of memory can cause variations in the co-researchers' description of experience. I referred the themes back to the original protocols in order to validate them, to ensure that the material of the protocols was accounted for in the theme clusters, and that the themes remained true to the original experiences, and did not propose further conjecturing. I began the organization of themes with one protocol, and then added others through analyzing the second protocol, and then the third, in a building block approach, until the description became full and similar amongst protocols (saturation). In doing this, the phenomenological description was created, which in turn revealed the common structure. This procedure was based on the principle of theoretical sampling (Glaser and Strauss, 1967). The researcher completes one

analysis, and then systematically adds another, until saturation occurs. In my own mind, I thought of the phenomenological investigation of experience as a creative process, in which more colours and strokes are added until the picture approaches completeness.

The next step was to integrate the results into an exhaustive description, called the phenomenological description, in order to represent the totality of the experience. The essential structure emerged from the phenomenological description; this is a condensed, unequivocal, universal statement about the meaning of adjustment to chronic pain. The phenomenological description and essential structure are included in Chapter Four. At each stage I re-read the protocols, synthesizing my understanding of them, checking between them and the emerging results, and ensuring fidelity to the original phenomenon as much as possible.

At this point, and after the protocols had been given to my co-researchers, we met again to discuss the findings. I wanted to find out if the phenomenological description had represented their experience in a true manner. I asked them to validate the phenomenological description, by adding or removing data, changing or clarifying themes; I took notes on our discussions. They all made statements such as: "It's right on", "You've covered everything", "It's exactly the way it is", "The kernels are there", "I like this, it pulls a lot of things together". One person suggested two changes which would emphasize points already made. These changes were incorporated in the final version, after ratification with the other co-researchers for consensus.

CHAPTER 4

Results

The Experience of the Researchers

The process of doing this study was impactful for me and for my co-researchers, and as with all processes, this study created thoughts, feelings, reflections and changes within us.

At the outset, before I started the interview process, I wondered how much involvement I would have in eliciting the information. I believed that if I was truly attentive and valuing of the information being presented, if I was fully present to the significant life experiencing being discussed, that the stories would unfold. In fact, when I began the interviews, I was left speechless at times with the finely honed reflections of the past twenty-three years in one instance. My co-researchers were not university educated individuals, nor had their life experience included a great deal of self-disclosure. The sharing was imbued with significant thought, growth and struggle. I was surprised at the amount of detailed material that emerged concerning intense life situations. I had the sense of saying very little, yet being very much a part of the experience. Frequently during the stories, I felt strongly with my co-researchers as they shared their struggles; I felt sadness and grief with them, and cried with them on more than one occasion. I was moved, at one time, when with tears pouring down our faces, we could see and feel the strength shining through of our selves and the other as persons in the world who had an effect.

I left several days' time between sessions so that I could reflect on my experience, and integrate what had happened. I was very involved in the process, and became aware that this experience was now a significant part of my life tapestry. My friends commented on my enthusiasm, resolve and energy for the project, as well as sometimes my sadness, and listened with interest to my experience.

The process of going from one story to the next, experiencing all the years of despair, and reliving the struggles, was very challenging for my co-researchers, and for me. There were moments when the overwhelming nature of the experience affected me. At the same time, I was energized, inspired, and given the enthusiasm to go on, through being involved in this study. My co-researchers and I shared a closeness in making meaning together; in fact, we sat close together throughout the sessions which was reflective of our

mutual, trusting exploration. I felt the inspiration that came from my co-researchers' stories of extremely difficult conditions and their "winning through" these times.

During the interviews, the process was constituted by much more than the actual words being spoken. I was aware of tone of voice, body language, facial expression, silence, as well as laughing, choking, coughing, crying, and sighing. At times, there was the tone of disbelief in a co-researcher's voice when relating a specific time. Similarly, exasperation, shock, anger and sadness were expressed by their presentation, as well as their words. The stories concerning their suicide attempts were particularly evocative; these stories are good examples of the vivid reliving that went on during the hours we worked together. They reflect the intense pain and struggling of the time. My co-researchers at times hit a table, got up and walked around, or changed positions, which added to the colour and emphasis of their stories.

Each co-researcher, on more than one occasion, gave unsolicited descriptions about the process we were involved in together. In fact, one of the themes to be presented in this chapter has to do with the difficulty of returning to their experience. They all shared that the dialogal experience had been a positive one for them. They were surprised at the amount they had shared ("Man, am I ever a motor mouth", "I feel I've never talked so much in my life"), and stated that the attentive listening and patience they experienced created a useful opportunity to describe in a full way their experience with chronic pain and to make meaning of this phenomenon.

My co-researchers and I all shared a sense that what we had done was valuable, for ourselves, and for others working with the experience of chronic pain. My life has been enriched by doing this study. My experiential base for living, and working with people, has been expanded and deepened. The inspiration which I have gained from sharing the intimacy of my co-researchers' experience has affected me in a very positive way, enhancing my energy and enthusiasm for attending to actual experience, and then translating this awareness into action in the world.

Themes

These thirty themes emerged from grouping significant statements and asking the question: "What do these statements have in common; what is the underlying meaning which is conveyed by these statements?" These themes, through the process of phenomenological description (in which the phenomenon is understood and clarified, see Methodology), form the basis for the emergence of the essential structure of adjustment to chronic pain. The phenomenological description and the essential structure are presented at the end of this chapter. I have listed the themes with significant quotations in order to allow the true and vivid sense of the co-researchers' experience to be illuminated. Some themes are not illustrated as extensively by quotations since not all co-researchers' descriptions directly revealed specific themes. The rationale for including all themes is provided by Collier and Kuiken (1977; See Methodology). All themes were ratified unanimously by the co-researchers in the phenomenological description.

1. Feeling Overwhelmed

Fear, panic, horror, and despair were all part of the experience.

I woke up about 4 o'clock in the morning, and couldn't move and I'd wet the bed ... I couldn't believe that. From my waist down there was no sensation. I kind of panicked.

I was devastated, here I was one surgery after another and I don't know it was horrid, I thought well this is it.

There was a terrible amount of frustration, a lot of anger because I felt that something had happened and I couldn't do anything about it ...

... to do just the simple ordinary things, I walked around the house holding on to furniture, because each step was like stepping into hell. The pain was just something excruciating.

I sat there one night and I just folded in the rails on the goddam bed. I was just in so much goddam pain I was just in tears, I couldn't compose myself ...

2. Being Lost in the Preceding Years

The co-researchers experienced a disorientation within their time frames; they discussed the length of the process, and the sense of being on a treadmill.

... what is happening? Where is my life? What is going on?

So I would say up until I came to the Centre all those years were sort of really lost ... a lot of times I felt like I was just one of those hamsters on their wheel going round and round and round, there was nothing, there was just no way of getting off.

It's really strange, because I remember things that happened but I can't put dates to them. And it's sort of like those years ... if I'm asked to document it as far as what happened in sequence I can't do it because it was so blurred most of the time.

3. Pain in Remembering

Our discussions evoke the painful, nightmarish quality of the preceding years. In the course of remembering these experiences, many feelings emerge.

I can't remember the amounts of time because it's something I've really put a lot of effort to forget. I don't want to think about that period in my life. There's parts in there, there's parts that I don't want to recall, and I'm finding it very difficult, to recall that, I really want to leave that. I find it very hard to go back to it. (Eyes fill with tears. Pause) I can feel the frustration building up again, the ... (sigh) ... both the physical, the emotional and mental pain keeps coming back when I have to go through it. But, you know, it's been several years now and I think purposely my mind wanted to block a lot of it out which is why I can no longer put it in sequence ... it was just so painful and everything was just so up in the air. They were not the best parts of my life.

I have gone over this so many goddam times, I go back and forth at nighttime, and I used to have dreams about it and I haven't in the last six or seven months. I put it away, it's a bad part of my life.

4. Feeling Unbelieved

People have had many years' experience with the medical system. They feel that doctors have assumed that they could not understand, and have expected them to accept treatment without question. They feel unbelieved, and like guinea pigs.

I had a real problem with the medical profession, I felt that they were beginning to look for an assassin.

... of course you get your bad in every element but Jesus it blew me away in the medical profession. And that's when it got to the point that I

thought that they were hiring guns to say that there's nothing wrong with you ...

And they kept telling me, "there is nothing physically wrong with you". "Why is it (anger) that I can't feel my leg?" "Well, there is no physical reason for that." I never found out what it was until after I read my file.

5. Confusion

People experience confusion with the many medical interventions which have not been explained to them.

I can appreciate why she's (wife) so frustrated because of the runarounds. She has been involved with the bad doctors or the bad contacts with doctors.

However, from the surgery on it started to be a thing of like I say months of traction, in and out of the hospital, medication, this doctor, that doctor, orthopedic surgeon, neurologists, and a this and a that ...

They went through more bedrest, more traction. I was sent home in a body cast ... for four months They took the cast off. There was no result whatsoever Depressing, like why have I gone through all this and you know I'm still not any better ... and in between all this time I'm constantly going to physio, I'm having ultrasound, I'm having heat packs, I'm being pulled, I'm being prodded, I'm in traction this way and I'm having everything like that.

So anyway, the doctor said what we'll do is we'll go in and clear the scar tissue out and see what happens ... still, I didn't know what had happened.

... they just automatically assume that you know everything and they just don't take the time to give you any assurance, you know, whether it was because they didn't have time or whatever, but I mean I was petrified ... and by one o'clock I was on the operating table and I didn't know what was happening to me ... he himself I really feel should have taken the time to explain to me what was going on. I didn't even know what he was going to do. I mean, and here is me signing this surgical consent form out of sheer fear. You know, all of a sudden this consent form, surgery, and I mean at this point I'm in tears, I'm crying, I couldn't even read what procedure was going to be done. I mean plus at this point they had me on a lot of pain medication and a lot of tranquillizers to keep me sedated. I mean, I legally should have never signed that consent paper because I was in no shape capable of making a decision ...

6. Feeling Abused

They feel that they have suffered as guinea pigs at the hands of practitioners who have expected them to accept treatment without question.

... somehow I realized, I've gone to a neurologist, and he'd given me medication, I'd gone to an orthopedic surgeon, and he'd given me medication, and my own doctor had given me medication. And at one point I got to thinking, now why do they want me to take all of this ... I never did find the answer to that. But I was taking the whole thing. I was on Librium, I was on Valium, I was on Dalwin, I was on Tegretol, I was on just anything that came along to the point where I thought I couldn't live without it ... their fault because they think they are above the ordinary person for not explaining ... nothing works, it's sort of like; well, there's another guinea pig, we'll try this, we'll try that, and if that doesn't work we'll try something else because they can walk out that door and forget about you. You're the one who is left with the problem.

And then there was a doctor down there who used to take me in once a week and check me over and I would (pause) just (pause) cry, literally, **scream** with pain, and the **tears**; in the positions he was putting me through.

I was in tears, in excruciating pain for the examination. I mean he over-manipulated my back.

The most painful part of that examination was when he took his hand down my spine, he started at the top and just literally went right down my spine like this (demonstration - thumb pressing vigorously, stabbing) for tender spots.

... like the days I was taking medication. You go up on the goddam thing and drop down 4 feet below what you used to be and it was just run all the way down. It was just like climbing a 35,000' trench and back up again and after three and a half to four years ...

7. Feeling Processed

They have dealt with the compensation system and have felt "processed", almost as a number, by a system which puts them through lengthy episodes. They feel frustration, anger, a sense of devaluation, and self-doubt. They all experience one contact which was helpful.

... I was requested to go in and I'd get comments like, you don't look sick; how do you expect me to look, the pain's in my back.

So I approached (them) and they said: "There's no way you can handle that. If I thought you could handle that, we wouldn't have told you you couldn't handle your other job." And I said, "Well, yeah, there's different types of pressures, but god, can't I even just try?" (Voice increases in pitch and volume) They said, "No, you can't even think about that ..."

... no one was really doing anything for me and then that lasted for, well up until I finally heard about the Centre and begged them (the W.C.B.) to send me and from the time I heard about the Centre to the time that they finally decided to send me was like eighteen months ...

... talk about the slow wheel.

I figured I needed help, I still had two young children, I had to get the family going, I needed somebody to talk to. I couldn't get the support from the Board at that particular level.

... I wish I would have gone through the Centre three or four years ago, maybe a lot of this heartache would never have come about ... I mean I was going through pretty heavy duty times then.

So then WCB thought they would put me out to Richmond. So I said to the Rehab guy ... "do you realize how far I have to drive, and I can't drive, I have a difficult time driving or sitting." So he said, "Well, you have to go to the Rehab out there and this is when you start." And it's over 30 miles out there and over 30 miles back. So I did. I had to be there at 9:00 a.m., so I left about 6:00 in the morning because I'd have to stop, and get out of the car and hang myself on the car to stretch my body out so I could keep going. I'd go down there and I'd have half an hour of gym with no instructions, just "there's the threadmill, there's the steps, there's the ropes, there's the thing that you row." And that's it. You signed in and you signed out of that, a half hour in the pool, and half an hour where they do crafts. And then back in the car and drive back home. This went on for (pause) 7 weeks ... nobody knew whether I was coming or going, it did not pertain to what I was dealing with...I felt like I was just a **thing** that sort of crawled in and crawled out, and that was it.

8. Difficult Relations with Co-Workers

They have felt unbelieved and ridiculed, which added to the hurt and struggle to get better.

I still feel some anger ... at C for not believing that I was hurt.

... prior to the injury I was so self-motivated and directed ... and the injury certainly slowed me down to the level that I was susceptible (pause) like I was weak, like a virus just took me over and I was susceptible to anything that went down, mostly to guys I worked with, their insults, criticism ... ridiculed by my peers mostly, challenged as to my ability, criticized ...

9. Feeling Overprotected

This leads to frustration, and a feeling that their world is shrinking, and that life, as they had known it, has receded.

People would say to me, "Don't do this because you are going to hurt yourself." Everybody became very aware of protection around me which was even more annoying because I was still, I still wanted to do the normal things but physically I was restricted.

I wasn't allowed to do this, I wasn't allowed to do that, so that was another big frustration. Don't do this because you'll hurt yourself. Don't do that, you'll hurt yourself. So that my world was getting smaller, and smaller, and smaller (anger), and I was trying to function in it, and the pressures were just really inhibiting me.

... I'm finding that's probably one of the hardest things at work right now is assuring people that I am all right because they tend to want to overprotect. You know, and sometimes I say, just leave me alone, I know I can do it.

10. Self-Doubt

The result of incredulity on the part of others leads to self-doubt.

... the upshot of it all was, "Here's some medication but it's all in your head" type of thing ... It just created a vacuum for me in such a way that I just stopped caring.

... Well, I got to the point where I started doubting myself. I started thinking well, geez, you know, maybe it is all in my head ... I thought well, maybe it is all upstairs. Maybe it's not really here ...

So then, I figured all the way through it was hot and cold, and hot and cold, whether it was in my head and I was sitting there talking to myself, now look, this is the way it is going to be, and if you don't do it you're going to get slapped around, and nothing ever worked.

11. Self-abuse

As a result of self-doubt, people begin to drive themselves, to prove to themselves that there is real difficulty.

... that's when I really started abusing myself because if my back would hurt, particularly even if I hadn't really done anything specific to hurt it or whatever and it started hurting again, well my attitude at that point was if you're going to hurt I'll give you reason to hurt and I just wouldn't let up. I mean I would just blank that pain out and I would just keep drilling myself, drilling myself and the only way I could keep on doing that was take more pills.

I'd vent my anger at the drop of a hat after the third or fourth year ... I put my fist through a lot of walls, thick walls, I had a lot of crying sessions.

And the only way I could justify shutting it down is by ending up in the hospital so I pushed it to that limit because I couldn't live with myself ... I pushed it to the limit so that I couldn't even function or move any more so that I'd have to go to the hospital

12. Consideration of Suicide

They all described getting to the point where they could not go on any further, and had thoughts of ending it all. Two consciously tried and failed, one abused drugs.

... I just thought to hell with them. They are supposed to be so educated and so smart and they can't help me ... I just sort of went into the vacuum and then became desperate. I really thought about suicide, I tried it twice, made the attempt I should say, I didn't get all the way because there always seemed to be an obstacle in that area.

Looking back at those years now it's a wonder I never ended up in some psych unit just with trying to cope with what I was going through...I had really given in to it ... I had just literally given up fighting for myself ... I just didn't care anymore.

I had a couple of close encounters with what I guess somebody might say suicide ... I'd literally knock myself out with pills to the point where sometimes I didn't remember how many I'd taken because maybe I would take maybe one or two but I still wasn't sleeping ... so that I'd end up taking two more and I'd end up losing track of what I was taking ... I was very borderline as to how I was before I came to the Centre.

And when I went down to that dock I was just, I was standing there thinking, how simple it would be to end it all, and all of a sudden a voice behind me said, "Are you all right, ma'am?" And I turned around, and there was, I don't know where the person came from, the dock was a **long** dock, ... I turned and looked at him and I said, "No, I'm not." And he just took my arm, and he said, "Come, and I'll walk with you." And he just walked up the dock with me.

... I went to put the car over the cliff and it got hung up on a boulder. And the car wouldn't move. It just wasn't meant to be ... I came around that corner and I thought this is it and I went to head off the bank. And that ruddy, the front end of that car (anger) got hung up on a boulder and the back wheels just spun great big holes so I couldn't do it either.

I was coming over the — bridge one night and it was just bang! it was just everything, I couldn't see nothing, just spots flying out, black and white and stripes and coated and green, and my hair was burning, it felt like it was standing on end, and I figured this is it, piss on it, I'm going over the edge.

13. Changes in Lifestyle

The things that for them were the ordinary things of life they were no longer able to do. This added to the stress, frustration, sadness and pain they were experiencing.

... I was on the high side, going, going, going, swimming, skiing, boating, diving, never had time for anything to catch up to me. When I got hurt I had to take a back seat for a while, so it was like dragging an anchor or like being weak. And the viruses came in and they got me.

... being very athletic prior to that, a lot of skiing, a lot of tennis, a lot of everything and I just felt like everything had been taken away from me and very angry, very bitter, at just the whole world.

... I (then) had home care nurses...having to come in and catheterize me daily At the same time the nurses were coming to the house three and four times a day to give me injections of Talwin for pain.

14. Family Involvement

The experience of dealing with chronic pain spread to the entire family system.

... the children were afraid of me, because there was no talking to me, simply because I was not being rational and I would just, if I got upset I would scream at them ... So it suppressed the whole family.

It's like when you're down, any virus can attack, our family unit got like that ... It went through my whole family setting, I mean it hit my wife, my children and we became like introverts. There was nothing great about anything we did around the house, we fermented and it got bad and I was getting medication for my daughter ... And she wouldn't go to school. There were horrible situations. My son, they couldn't handle him in school.

From the awareness that the family has been involved in the experience of chronic pain comes the realization that rebuilding will be occurring. They discuss their responsibilities to their families, which assist them to keep going in their search. My co-researchers describe making up for lost time, making amends, attending to and appreciating other family members' needs and processes.

I think the only one person that never let me get super down, that really kept me going even though I was letting myself slide, I never let myself go all the way, was my daughter. Because there was that one part of me, that one maternal part of me that knew I had someone that was depending on me, so I was really down but there was this much of me still wanting to get better.

There were three other people counting on me and I am responsible for those three other people otherwise I probably would have wasted myself.

Then, I had to pick up the pieces. And I had to start building fences. I was spending a lot of time with my children talking to them, dealing with the things that I did to them.

I've got to be thankful for my kids. I really do, in spite of the things that they went through, I at least now have the opportunity to talk with them about it and share with them what my feelings were then because they are still very vivid.

I also find that lately my children have been coming to me not as so much coming to mother but coming to a person that they can feel free to talk to which is a very good feeling. It feels really good and my daughter said to me one day, "Mom, you know, it's really nice to have you for a friend", and I thought (voice breaking) "oh, wow, I crossed a threshold, I don't want to look back, I don't want to even see what's back there."

... I spend a lot of time with the kids every weekend now and find that's a mutual escape, so that works for us.

I think it shows the direction that we're going, to do something as a family ...

The family unit and all of us sharing ... when we take off camping and things like that.

15. Struggles to Get Back to Work

They all described their attempts to get back to work, which was important for them, and the price they paid for their efforts.

With that I tried to work but it was really hard ... What would happen was that I would work a straight shift for a period of time and then I would when it would get bad I would just go in part time. As long as I was able to cope, keep things going. So it was just a matter of trying to fit life into what I recognized was now already a chronic pain syndrome.

I'd get back to work and maybe I'd be back for I think tops was, the last time I made it back I was back for almost two years prior to that it was you know three months here, five months there, six months there ...

In the beginning I fought, and fought like hell to get back to the level. I made numerous attempts to get back to work, sometimes sitting up in the bathtub soaking for three and four hours ... I robbed my home life dearly just to prove that I could get back to work, to put food on the table.

16. Feeling Alone

The struggle of dealing with chronic pain is a lonely one.

... I felt as though I stood so much alone. And I did, I stood absolutely alone.

17. Desperation for Help

They all described an intense yearning and need for assistance to make changes because their situations were intolerable.

I really thought, I've got to find something else, I've got to **do** something else.

I've got to get help somewhere else.

I had been really wanting, I mean there was no way I could keep going the way I was, something had to be done ...

It was a mess to go through, it all piled up. I was just begging for help at times, I was just literally begging for help.

I was always grasping or searching for an escape or somebody to talk to or for help, always, always. I humbled out after two or two and a half years and then I actually asked for help, and I always asked for help ...

18. Finding Caring, Nurturing, Teaching and Validation

They all discuss the importance of being listened to, heard, understood, believed and validated as human beings, and the strong effect of perceiving oneself to be in a supportive environment. They no longer felt alone.

And by my second week in here I knew I had the answer because for the first time in nineteen years somebody cared about what was really happening to me ...

But here I found the answer, the answer was it was up to me. That somebody cared enough to show me ... You have no idea (voice shaking with power) how actually thankful I am that this existed because I know for a fact that I would not be here today, I would not be, if this had failed I would not be alive today. I know that as certain as I'm sitting here because I couldn't go any further.

So whether it was the warmth I felt, or whether it was finally the caring, whether I was the weary traveller that had travelled so long and finally came to an open space..

... all it took was a little bit of nurturing and a little bit of saying yeah, it's okay to feel that way for me to really start getting in touch ...

... the full attention and I think I really could find someone somewhere that cared for me as a human being, that cared for me as the person I was and for the things that I had to offer ...

You know, I just felt my God, there's finally someone, number one that believes me, that there is pain ...

The people on the staff are concerned people which is great, nice actually, motivating because I hadn't seen anybody in the medical profession concerned since I was in the hospital when they took me to the General when I was injured.

This nurturing, belief, attention, support, validation of the individual as a worthwhile person, leads to seeing the light (an image used by two co-researchers).

... I was so enmeshed that I had no way of seeing the light and then somebody lit a match and that's where I went, I went to the light and that's where you've got to go, you've got to go to the light and the light is within you.

... there is a light at the end of the tunnel and it's quite bright right now ...

... to reopen that light at the end of the tunnel, to travel in that direction and put out the fires that were in my way.

19. Motivation to Get Better

They discuss the importance of wanting to get better, and then using the resources made available, and applying oneself to the process.

... I just knew that I had to give this everything I had.

... I had to choose whether I was going to take it or not. And I decided right from the start that I didn't care what they showed me, I was going to try it because nothing else had worked ... I just gave it my all and in my second week I knew that I had found the answer.

I had to accept the fact that there was nothing further surgically or medically that could be done for me so I had to accept that and then thirdly I had to want to get better and because no matter how good that programme is at the Centre if you don't want to get better you're not going to.

... they were so terrific and I could see that they had so much to offer. I was determined to take advantage of just everything. It was like a whole learning experience, I wasn't going to miss out on anything.

... I was determined that I was going to leave there with all the tools ...

... I am fortunate, I'm back to work and I give a lot of credit to the treatment that I had in the last while ... and I give myself a lot of credit too because I put everything I got into being back and you need that. You only get back out what you put in ...

I've put everything that I could possibly put into getting (pause) I had goals when I got in there ... but I was motivated ...

... when I went into the Centre I resigned myself to the fact that there is no other recourse man, this is it. Whatever comes out of here is either going to be positive or negative but whatever it's going to be it's going to be final ... so there was a strength, for me, a real strength in there, and the cooperation and help from the people, the patience and the time.

20. Feeling Self-esteem, Value as a Person

They shift the focus from others to themselves. They begin to appreciate their worth as people.

I don't think I'm much different a person, I still do and I still care and I still go along the same route that I used to go but now I care about me more than I care about what I do to someone else.

... I'm happy with who I am. I am pleased with what I'm doing and pleased with me and pleased that I am in control ...

I give myself credit.

I'm special to me.

21. Feeling Freed by Knowledge

Knowledge gives a sense of control, and sanity. The facts are known, and can be dealt with, whereas the unknown has affected them negatively.

... I don't fear my pain now because I know what is. I know what the different surgeries, I know what they did when the nerve was cut, I know now that I was not crazy, it was not in my head, it was a physical thing even though it was grossly overrated within myself, but I believe it was because I didn't have the knowledge. It's the knowledge that made me free, gave me my freedom ... my control is there. I had it all the time except that it was bogged down with other people's thoughts, opinions and innuendoes as to what they thought was wrong with me. I now know that I know (emphasis) what's wrong with me and I can deal with that.

22. Shifting the Focus from the Pain

The pain is no longer in the driver's seat, no longer in control. The individual has knowledge, insight and skills to take control, and lead the life, rather than the pain leading the life.

... just being able to control pain, because I found before the Centre I spent so much time and energy with this pain that I had no energy for anything else. I mean it was just like my whole world was centred right on that one low back area, and I was so busy protecting it or abusing it, I'd be protecting it on one hand and abusing it on the other hand by not treating it properly with body awareness and the whole bit, that I had no energy for anything else ...

... whether it be my back pain or any other pain that I may have in the future I know that I will be its boss. It's not ever (forceful) going to be mine, not my master again and I know that just from way down in my gut.

23. Growing Self-awareness

Self-awareness is a process which comes from reflecting on experience, and then using this insight to make changes.

... I need to be aware of my first feeling ... I even utilize my dreams in a preparational way ... I feel that awareness so that whatever happens I can deal with it ... I have sharpened my awareness because I've listened to what my body was saying to me and my head is part of my body.

... if I can dig half a garden one day that's fine, it doesn't matter, the weeds can run over the other half because I am comfortable digging that part and then I hear what my body is saying. Great job, I'm glad you got this far, however, and I put things away and walk in the house and then I do what I need for me ...

24. Assertion

They realize their own feelings and rights, and stand up for themselves. This process leads to taking action, dealing with experience in a different way, asking for information to make decisions rather than complying with professionals.

... they know that they can't walk over me, nobody, and that includes my husband. I'm not being the doormat anymore, I'm not trying to please anymore because I know that if I please everybody else and don't please myself then it's hollow. If I do something to please me everybody else benefits ...

I did have an appointment with Dr. — after I read my file. I went back to him I made just an ordinary appointment and I sat down with him and I said, "You know, you bastard, if I could I'd sue you, why did you not tell me that this was what happened and this was what was causing it. Why did you

not tell me that nerves repair themselves. Did you think that I was so stupid that I wouldn't have understood?" And he said, "Well, you know if we took the time to teach each person or to tell each person that we do surgery on we'd never have time to do surgery." And I said, "well, that's your problem not mine ..."

... whatever the situation is I need to take action on something and as long as I take the action I can sail through.

The more that I was learning I was becoming very angry at the doctors for not knowing how to deal with pain. ... I said I'm just amazed, I said you guys can do so much as far as all these new techniques ... but you still treat chronic pain as if it was acute, ... and I said really, I'd be very interested in knowing how many of you guys sitting at this table have been prescribing pills for some kind of back pain for longer than two months. I said I'm talking twelve months, eighteen months ... you've written out more prescriptions ... Three of them said "I'm guilty" ... I said you know the definition of chronic pain but you're not relating it to your practice ...

... that was the first time I ever questioned what a doctor said to me any time in my life. I mean, they've cut me open, they've gone in, they've done anything they wanted, I became a very conscious person after that. A long conversation before anybody went inside me again ... did I ever ask him a hell of a lot of questions and got answers and I said you know, you don't mind if I qualify these first and get other opinions and what have you.

25. Immediacy

They all discuss the importance of dealing with things "right off", living in the moment, not deferring reflection and action.

... I need to deal with things right off, if something happens now I need to deal with it now or as soon as I possibly can, I can't leave things for days and weeks or months.

... whenever anything comes up I deal with it immediately, I don't harbour things, I don't harbour frustration ...

... what is useful is where I am right now ... whatever is required of me then I will deal with it daily and that's why I think it works. You've got to deal with today before you can deal with what is down the line ...

I just have to take them as they come ...

26. Realizing Assets and Using Strengths

They discuss the importance of realizing that they have capabilities and strengths, and using these assets to reach out and go on.

... I need to be me as a person, I need to cultivate all the capabilities I have, that I have buried over so many years and dug under and stuck in holes and put away on shelves. I need to be who I am, I need to know and live with the capabilities that I have ...

We all have strengths, it is what we do with those strengths ... until I took and put everything in its proper perspective and once I did then the spirit of strength, the spirit of all the things that go to make me were able to surface. I took the crust off of it.

I'm actually quite humorous when I go home. I have a lot of fun on the buses when I ride on them too, so I'm really getting people oriented again which I think is a real asset and I enjoy it.

I'm back, I laugh a hell of a lot, I laugh more than I've ever laughed in the last five years. I tell a lot of jokes, I play around quite a bit, I kibbitz, I've got a hell of a rapport with all of the working people ...

If you've got something that you can offer, there's got to be something in everybody that somebody can offer. There's got to be a talent or an ability.

27. Doing Something of Value

By taking constructive action, they feel good about themselves, useful, and in control.

We can't relive our lives, we just have to make sure that what we do have to live we live with giving it value and meaning and doing something constructive with it instead of just going from day to day and doing nothing. I want to leave something of me behind that's going to mean something to somebody somewhere, whether I know that or not, but I want to be able to do that.

I share it with the people that I talk with on a day-to-day basis ... I share my experiences and they, a lot of them, are very interested ...

28. Looking at Alternatives

They realize there **are** alternatives, choices, possibilities for change, and adjustment.

... if this happens, if that happens, if I don't get this job, there is this and there is that that I can do, there's so many alternatives to the worst thing that can happen. It all boils down to just bloody material things, that's all it is, and I don't know of anyone that hasn't come through one way or another yet anyway. Sure they have had to change their lifestyle, they may have had to change their dreams, they may have to change their wishes, they may have had to change a lot of things, but changing those things to be comfortable, there is no money in the world that can buy that and if you're comfortable then other doors open for you but you've got to shut your old garbage out first before you can open new doors and that's how you have to deal with it.

29. Unity of Mind and Body

They find that they work with their bodies, rather than abusing themselves. They are functioning as a whole being, their thoughts and actions are congruent.

... You're not doing your body any big favours by drilling it or by ignoring the pain. The more you ignore the pain the more injury you're actually doing. You just have to stop. I mean, obviously the pain is trying to tell you something so listen to it and learn how to deal with it and then how you go about dealing with it.

... I guess that was one of those highlight times when I discovered that my feelings and what was coming out of my mouth were in tune with one another ... I really started to think about what it was that was down there that was able to come up and it felt good, it was in tune, in sync with one another, you know I wasn't feeling one thing and saying another, that struggle wasn't there.

30. Gaining from the Experience

From the many years' struggle comes a sense that they have gained something from the experience, a contact with a force beyond the self, learning, closer family relationships.

Okay, I believe there is a higher entity than we are, I really do. I don't know and I don't care how anybody else thinks about it. When things get too heavy for me I turn it over and that entity can be any shape, form, or anything that anybody wants to make it but I think there is something there ... that's where we get our strengths, that's where we are guided from ... I really feel there is something ... that supplies us with everything we need, it's us that are fools that don't use it ...

And (pause) I used prayer, I really did. I just said, Lord, I can't handle it. I'm turning it over to you. I can't take it. That seemed to give me some

peace of mind.

... my life has found a sense of value through that long, long struggle of pain and I'm now going to do something with that value because it's been gone for so long, it's just been subjected to such a depressed state for so long that I want to live two days every twelve hours because I want to put that much into it. I feel I have so much to give and I want to give it, I need to give it, I have to give it. I don't have time for the other, that's mundane ... Maybe I needed to go through all of that to be who I am today, and I'm special to me. Whether I'm special to anybody else it doesn't matter but I'm special to me and maybe that was my path.

Maybe it was a godsend that the injury happened, maybe that's what we needed ... maybe it wasn't going to happen that way before, I don't know, I've been looking at things like that.

I guess we need these little setbacks once in a while, eh?

... it's been a real learning experience. It's something I'll be able to share with my family and my children because they've been there at this level now and now I can show them some good times and when they get a little older ... I can explain things that I've learned over the past five years. And when it comes to stress I can share a lot of the exercises. I share my quiet times with them, too, my autogenics and stuff, it's pretty good for them to start at that age, it prepares them.

The themes which emerge from my co-researchers' experience can be viewed as pivotal, or as transitory, dependent on the cultural context. The fact that some aspects of the experience could be changed, and are not intrinsically part of the experience, demands changes in practice, as well as in theory. If people felt, for example, believed by others, not abused, processed, and confused by systems which were set up to help them, their experience of adjustment to chronic pain would be different. People would not be so desperate for help if they had experienced assistance at an earlier stage in their adjustment process. The basic components of dealing with the overwhelming nature of pain which does not end, the sense of being lost, and then finding the way again, remain as core constituents of the experience. In listening to my co-researchers, all these themes emerged, yet some, if we **really** listen, and make changes based on our awareness, could be removed from the experience of adjustment to chronic pain.

Phenomenological Description

The phenomenological description emerges from the weaving together of the themes. This representation of the total experience follows.

The initial injury and resulting pain create many emotional reactions for people. They feel frustrated and powerless since they can do nothing about what has happened. They feel a devastating sense of loss, and the fear that life, as they had known it, is over. Simple activities result in excruciating pain, and the sense of immobilization pervades. They feel panic concerning the trauma; for example, at not being able to move, and at not being able to control the pain.

People experience a sense of disorientation in terms of the time frames of their lives. The length of the process between injury and getting better is long, and filled with abysses. People feel lost in the years' long struggle, unable to put events in sequential order, and as if they are on a treadmill. A feeling of being an oddity is experienced.

The experience of the preceding years is difficult to remember. The confusion, the sense of being lost, the pain, the frustration, all contribute to people's desire to forget that period of their lives, to avoid returning to those places. People have tried to put away the experiences which have seemed like nightmarish parts of their lives. In the process of discussing these difficult experiences, which they would prefer to block out, people cry, choke, express anger and experience exhaustion.

People feel unbelievably, and that they are being told there is nothing wrong with them, after their many years' experience with the medical system. During the experiences with medical professionals, people have the sense of being on a lengthy merry-go-round of treatments, specialists, and various interventions. Practitioners do not explain the processes to them, and they feel fear and frustration. The people feel as if the treatment givers have been irresponsible, and they themselves feel like guinea pigs. The very painful procedures they experience, as well as the disorientation of large dosages of medication, erode their confidence and trust in medical professionals. They all experience one helpful contact within the medical system which has provided a focus of hope.

People have the experience of incredulity on the part of the compensation system's representatives. This is felt to be devaluing, and leads to a feeling of frustration, hurt, and self-doubt. They experience not being helped; the length of time which passes before help is received, as well as the numbers of people seen, contribute to the feeling of being

"processed" by a system which puts them through a series of runarounds. They do find one positive experience, within the process of interacting with the system, which helps them.

Contacts with co-workers have added to their struggles to get better and to deal with their disabilities. They feel anger at not being believed by their peers. They also feel attacked by insults and criticism. This lack of support from co-workers has added to their difficulties.

Others, especially family members, begin to overprotect them, which they find to be frustrating and annoying. When others are constantly suggesting that they not do things, they feel a growing sense of impotence, and existential claustrophobia, as if their worlds are shrinking. This treatment by others is perceived to be undermining, and foists the "invalid" (not valid as a person) role on them.

Through the contacts with care-givers, and the length of the process, they begin to question if what they are experiencing is "all in their heads". Self-doubt increases to the point of being an eroding vacuum. The effect of this self-doubt leads to people driving themselves, almost with a sense of self-punishment, to prove that it is not just "all upstairs". There is a sense of giving up.

People begin to abuse themselves, to create a tangible reason for their suffering, and to try to force recovery. Their anger at not getting better also leads to self-abuse. If they push themselves beyond their limits, so that they are incapacitated, they can avoid the nightmare of self-doubt, and can "legitimize" asking for help.

The pain, the turmoil, the attitude of others, the devaluation of self all converge to the point where they consider ending it all. Whether through conscious attempts to kill themselves, or through abuse of drugs, they try to terminate the process which has become interminable and intolerable for them.

They experience dramatic changes in their lifestyles, from being very active in sports, recreational, family, and household activities, to feeling immobilized. They experience despair and anger with the loss of their previous way of living, and the struggle to keep going with their limitations and altered lifestyles. The experience of chronic pain, with its accompanying lifestyle changes, has impact on their family members. The entire family system feels the reverberations, marked by feelings of being withdrawn, suppressed, and anxious.

They struggle to return to work, which is valued, normalizing activity from which they derive feelings of self-respect and worthiness. They push themselves to attain this goal, and pay the price of increased suffering, and increased difficulties at home. The process of dealing with chronic pain, and being separate from their previous "normal" lives of working, recreation, and family involvement, is a lonely one.

People experience more and more desperation for help, an intense yearning and need for assistance so that they can make changes and gain some relief from the way they are experiencing their lives, experiencing which is marked by growing despair. There is the imminent sense that things cannot go on in the same way, that something else has to be done. Within this desperation, people are affected by something outside of themselves which assists them to keep searching, rather than ending the process. Family responsibilities, and belief in a power beyond the self, help people to continue struggling to get better.

Finally finding caring, nurturing, teaching, and validation is crucial in their gaining in their battle to improve. Being listened to, heard, understood, believed, cared for, validated as human beings, and feeling themselves to be in a supportive environment, are extremely potent for them. It is like a sense of homecoming after many years, finally someone cares what is really happening to them, and believes that there is something happening to them. They no longer feel alone in the struggle. The answers come through information sharing in a warm, accepting, concerned atmosphere. People gain a sense of seeing the light which is facilitated by experiencing the support of caregivers who appreciate that they are worthwhile people with things to offer. Finding this environment inspires greater motivation to get better. First, it is important to **want** to get better, and then one must accept and use the resources made available, and apply oneself to the process. They are determined to "give it everything they have", and to capitalize on all the opportunities to learn and grow.

As they begin to feel more possibilities in their lives, and as more hope filters into their experiencing, they realize the importance of doing rebuilding work in the family. There is a sense of making up for lost time, making amends, attending to and appreciating other family members' needs. They do more with their families, they communicate with them, and there are positive results to these efforts.

People begin to feel better about themselves, and to experience their own value. They shift the focus from others to themselves, and give themselves credit for the changes they have made, and the endurance they have brought to bear in their struggles to deal

with chronic pain. They appreciate themselves, and this appreciation of their worth provides a foundation to continue to take control in their lives.

As people gain knowledge about themselves and their conditions, they begin to feel more in control, and gain a sense of relief that comes from **knowing** that they know, rather than the "feeling crazy", doubt, and fear which accompany lack of knowledge. There is freedom in knowledge in that the facts are out in the open and people have something tangible to deal with. Along with gaining knowledge comes a shift in focus away from pain. The pain is no longer the mediator of experience, it is no longer in control. People have knowledge, insight, and skills with which to take control, and live life, rather than the pain leading the life. Knowledge and shifting foci enhance the growth of self-awareness. Self-awareness is a process which comes from reflecting on experience, and then using this insight to make changes in the approach to experience. People attend to their first sensing of things, the messages they learn from their dreams, and what their bodies say to them. As they sharpen this awareness and tune into it, they adapt their activities, and do what they need to do for themselves.

Assertion develops for people as they proceed in their processes of dealing with chronic pain. By attending to their own feelings, they realize the importance of standing up for themselves. They become assertive especially with doctors who, in the past, they have not questioned. Now they discuss their feelings with doctors, challenge them, ask questions, and look for other opinions and options. Assertion leads to taking action, dealing with experience in different ways, and searching for information with which to make independent decisions, rather than "going along" with professionals.

People describe the importance of immediacy, the need to deal with things as soon as possible. It is no longer viable to harbour feelings. They live in the moment, dealing with the required things as they arise, rather than deferring reflection and action.

It is important to realize that they have capabilities and strengths, to nurture these assets, and to be who they are. Recognizing their strengths is an empowering process; they use their assets to reach out and go on. As they get in touch with their strengths and capabilities, they are aware of the importance of taking constructive action, doing something of value, making a difference through their presence in the world. Taking positive action assists people to feel good about themselves, they focus on the positive aspects of experience, they feel useful, in control, and coping with pain is facilitated.

People realize that there are alternatives to the way they have been leading their lives. There are choices, there are possibilities for change, there are adjustments which can be made. People come to value other things, such as being comfortable in the present with their feelings and situations, in addition to the material securities. They change their lifestyles, and make adjustments, in accordance with their realization of the value of being content with themselves.

Unity of mind and body occurs when people are attending to their bodies' messages, and existing in harmony with their bodies, rather than driving themselves. This harmony leads to a feeling of being "in sync": feelings, thoughts, and actions are all in tune. People are functioning as a whole being, with the body as a respected part of the whole.

Throughout the long struggle of pain comes a sense that there is value in their experiencing, that perhaps things have happened for a reason, and have been ultimately helpful and strengthening. There is a feeling that something exists beyond the self which holds people back from suicide, and which gives meaning to their painful struggles. These experiences are seen as a "godsend" which make them the special people they are now.

Essential Structure

The essential structure, or universal statement, is the condensed distillation of the phenomenological description, and is presented at this point.

The injury and resulting experience of pain create devastating feelings of loss, panic, fear, powerlessness and frustration. There is a sense of being disoriented in time; people feel lost on a treadmill, unable to document occurrences in sequential order, and ask themselves "What is happening to my life?" They experience the pain of these past years anew as they describe them; they have tried to forget these difficult, nightmarish times.

Contacts with doctors, on the whole, make them feel unbelievably; they feel as if they are given the runaround, not informed, abused, and treated like guinea pigs. Contacts with the compensation system add to the feelings of self-doubt; they feel "processed" by the system as "things" not human beings. Individuals from both systems have been helpful to them. Disbelief, ridicule, and criticism from co-workers create more hurt and pain. The overprotective attitude of others, especially family members, is frustrating and annoying; people experience existential claustrophobia, their worlds shrink, and they are treated as invalids, which is further invalidation.

Through the contacts with others, as well as the length of time, people begin to feel the erosion of self-doubt; is this really all in my head? People begin to abuse themselves to create a "reason" for their suffering and to create the hard data to allow them to ask for help. The constant devaluation of the self, as well as the constant pain and turmoil, result in attempts to end it all.

People experience drastic changes in their lifestyles, and feel the loss of the way things were. Their despair and frustration at their changed situations are reflected in the family system which has felt the impact of the changes. The struggle to get back to work is a painful and costly one, personally and within the family. There is a sense of loneliness in the struggle. People become increasingly desperate for help; things cannot go on as they are. They are assisted to continue by the sense of something outside of themselves: responsibilities to others, and belief in a greater power.

Finally they find belief, understanding, care and validation in a supportive environment. They no longer feel alone. A light appears at the end of the tunnel. They gain information, and are determined to use their resources to improve their situations.

They attend to the process of rebuilding their families, and appreciating other family members' needs. They begin to experience their own value as people. Their growing knowledge frees them from self-doubt, and assists them to shift the focus away from pain.

They gain in self-awareness, through reflecting on their experience, and listening to themselves, and use this awareness to make changes. They become assertive, and take action in their lives. They question doctors, and confront them, searching for information with which to make independent decisions. They deal with things as they arise, and live in the present, without deferrals, as much as possible. Strengths and assets are appreciated and used to reach out and go on. As they get in touch with their capabilities, they realize the importance of doing something of value. Taking constructive action leads to a realization that there are alternatives in the ways people lead their lives, and that being content with themselves is an important value.

People begin to function as an integrated whole. Out of the long struggle of pain comes a sense that the experience has been valuable for them in making them who they are, and that something exists beyond the self to guide people to growthful experience which makes them special.

CHAPTER 5

Discussion

The purpose of this study has been to understand as fully as possible the phenomenon of dealing with chronic pain. In the preceding chapter, an exhaustive phenomenological description, as well as a distilled essential structure, were presented. Inherent in the results are several implications for conceptualizing chronic pain. My own thinking about the process of coming to terms with chronic pain has been clarified, stimulated, inspired, and made more vivid through my participation in this co-researching. In working with the results I have also looked at the literature considered in Chapter Two as it relates to the findings. The study also illuminates implications for others with chronic pain, implications for practice, and implications for further research. This chapter will address these areas.

Implications for Further Thinking about Adjustment to Chronic Pain

The thematic constituents which emerged from the process of co-researching provide a great deal of raw material for thinking about adjustment to chronic pain. The phenomenological description weaves these theme units into a synthesized whole representative of the universal experience. One of the most striking effects for me in engaging in this co-researching was a strong realization of the **intensity** of the peoples' experiencing. The devastating disruption in their lives evokes feelings of a life-or-death struggle. The intense feelings surrounding the experience must be realized and acknowledged by people working with adjustment to chronic pain, whether as principals or helpers. Writers in the field talk about treatment variables, but not of the searing reality which individuals challenged with chronic pain are living; this study points to the need to appreciate deeply the experiential meaning of adjustment to chronic pain, and the importance of the individual, rather than the norm.

The experience has shaken people up: they have had to deal with the shock; with the frustration of not being able to do what they were previously able to accomplish; the change in lifestyle marked by increased isolation and feelings of loneliness, with negative impact on the family; dealing with the unknown, and the resulting feelings of self-doubt; concern about the future, "this cannot go on". The devastation of the experience lays bare the ground for asking questions about life, the value of life, and personal belief systems; there exists the opportunity for considering different ways of looking at life, and valuing

one's experiencing. People consider doing things differently, or finding different things to do. The self-awareness which grows from confronting the devastation is like a map: the more that is known about the self, the more options are perceived for planning and potential adjustments. Being in a supportive environment where learning and change can take place, with others in a similar situation, has great importance. The bonding, encouraging, and caring facilitate people drawing on the best within themselves, and reaching out to others.

One of my own assumptions before embarking on this co-researching concerned inspiration, and deriving hope and motivation to continue in the struggle. I believed that the people I was working with were "survivors" and possessed significant strength to negotiate the length of struggle which they had endured. These thoughts gained vivid clarification and ratification through working to create meaning with my co-researchers. They discussed the strengthening effect of the experience; they considered that it had a purpose in their lives, and that this purpose connected them to thinking about a power greater than themselves.

Relating the Literature to the Results

The meaning of adjustment to chronic pain as it emerged from the co-researching is based on the fact that adjustment is a process, not a fixed state; this finding is in line with the discussion of Roessler and Bolton (1978), and Trieschmann (1980). People experienced growth and change, rather than an arrival at a static end goal. Wright (1983), Stubbins (1977), and LeShan (1977) all discussed adjustment in terms of self-esteem, and a strong sense of the self as a valued person. The co-researchers experienced the importance of self-esteem; they begin to feel better about themselves through appreciating their endurance and the changes they have made. This self-validation provides the framework for continued progress.

The results did not evidence the existence of a stage theory for adjustment to chronic pain. The phenomenological description, which emerged from the co-researchers' work of creating meaning from their experiencing, does indicate important aspects of that experience which have implications for adjustment; this experience cannot be broken down, however, into finite sequential stages of functioning, which would then put into motion a mind-set and grid of expectations through which people's experience would be construed and evaluated.

Wright's (1983) discussion of adjustment as a learning process based on value changes facilitating nondevaluation of the self, relates in a general way with the findings (subordinating physique relative to other values; enlarging the scope of values; containing disability effects; transforming comparative status values to asset values). The co-researchers were involved in changing their lifestyles; they were high-achieving, active people before their injuries, and valued performance and physical activities. They could no longer do things in the same way, and reached out to find other activities from which to find value. They used their abilities to assist others, they became more involved with their families, and they invested in their own personal development. They worked to contain the effects of their pain, and to combat the "virus" from spreading to immobilize their entire experience, and their family system. The co-researchers realized that they benefitted from appreciating their current strengths and capabilities, and utilizing them, rather than comparing themselves to the way they were before the injury.

Roessler and Bolton's (1978) positive striving model, although it presents problems owing to the difficulty defining and measuring accurate perceiving of reality, self-actualization, and so forth, did relate generally to the findings especially with regards to co-researchers' feelings of growing adequacy in interpersonal relationships at work and at home, and their efficiency in problem solving.

LeShan's (1977) work comes closest to the results of this study, based as it is on listening to individual people, believing in them as creative beings with potential, and accepting peoples' experiencing as trustworthy.

When the considered literature is related to the findings of this study, it is clear that discussion of adjustment, especially stage theories, has been limited to only certain aspects of the experience. The discussion is similar to some facets of my co-researchers' experience, in a general way, but when seen against the reality of peoples' actual experience, the discussion remains one-dimensional. The difference can be characterized by contrasting generalizations made around the edges of experience, with being involved in and enlightened by the experience itself. The present study reveals the intense pivotal characteristics of the experience of adjustment to chronic pain, and points out the fact that to create theory, one must listen to people, and understand with them the meaning of their experience, so that theory is grounded in reality, and will provide the basis for acting, and working with people, in more sensitive, creative, and positive ways. This study provides a wholistic, vivid, thorough description of the phenomenon which is full of meaning.

Implications for Others with Chronic Pain

Toward the end of our interview, I asked each co-researcher to speak to others who are dealing with adjustment to chronic pain, and offer statements that would be helpful to others based on their own experiencing. They speak from the intensity of the years' long struggles they have been involved in.

I'd be candid. I'd have to go back to my past which has helped me through this turmoil ... I've seen people, all I can say is ... there are people worse off ... Go down there and see it for yourself. I don't relate to pain as much as I relate to hunger, people wanting and not having ... you can't sit and mope and whine on your own. There are people worse off ... you can't just wither up and die. If you've got something that you can offer, there's got to be something in everybody that somebody can offer. There's got to be a talent or an ability. Maybe sometimes that's got to be pointed out to them or highlighted.

I'd recommend the Centre to them ... I've had different people at work actually come up to me and ask me to teach them what I know ... I tell them a lot about the body awareness and you're not doing your body any big favours by drilling it or by ignoring the pain ... the pain is trying to tell you something so listen to it and learn how to deal with it and then how you go about dealing with it ... all you have to do is fall off the wagon a few times as far as not doing your exercises and realize how quickly everything comes back.

The only way a person can do that (get to a place of control and value) is to get in touch with their inner feelings and start doing something about those inner feelings and not push them aside in preference of feelings of pain. It's like a flower has to start from a seed, a seed springs into a stem, a stem springs into a bud, a bud springs into a flower. If you don't start at the gut level and find out what is in there you can't get to the outside because you can't start from the flower and go to the seed ... It's from the gut inside which means your personality, your thoughts, your fears, your anxieties and all those things that you would rather not deal with. You've got to go there and you've got to take your little box and you've got to open the lid and you've got to look at it whether you find a diamond or a cobra in there, you still have to do it and until you open that box you can't deal with it, you can only wonder about it, dance around it and do anything you like ... you've got to learn how to feel what it's like to come to terms with something you can't do anything about, something that is past. You've got to come to terms with do you want to carry it or do you want to let it be. Do you want to put it in its proper place, is there some unfinished business about it, is it worth the effort of finishing that business or is it just as easy to let it go and learn from the experience that because that happened you have something more because it happened and utilize it. Take the good out of the bad. The last thing you can do is pity yourself and say "why me?" That for me I guess, that's the beginning because I have to say why me? and that's when I had to start thinking.

You have to start asking questions of yourself, of people around you, you have to listen to those answers, you have to digest the answers and you have to learn to take all the good out of everything you hear and discard the bad.

My co-researchers talk about realizing their abilities; taking action; reaching out to others; keeping perspective; making decisions; maintaining a self-management program; receiving supportive, challenging help; exploring and clarifying inner feelings; nurturing self-awareness; using experience with the self and others as a resource for growth; and utilizing abilities in a meaningful way.

In underlining the importance of receiving help, and when considering the co-researchers' experience with helping professionals, one significant implication for others is the choosing of care givers. At the outset, it is important to be able to work with a helper in a positive way, to be able to ask questions, to be able to assert one's own point of view, and to seek other opinions and solutions.

Implications for Practice

My co-researchers described their desperation for help, and stated that they would not have been affected to such a devastating degree if they had had help earlier. Practitioners need to listen to the people they are working with to learn what constitutes helpfulness in the people's experience. This will prevent practitioners from victimizing their clients by imposing self-structured theories not grounded in the reality of experience.

People adjusting to chronic pain are not cases to be processed, but human beings struggling with different meanings in life, with making changes in values and belief systems; the impact of genuineness, involvement, belief, empathy, caring, positive confrontation, mutual exploration, and problem-solving on the part of helpers in this intense process, cannot be underestimated. Wright (1980) discussed the fact that circumstances can enormously increase or decrease the extent of a disability. Practitioners are encouraged to consider if their help contributes to the spread of negative effects, or to the person's ability to adjust.

Self-esteem is extremely important in people's adjustment to chronic pain; practitioners must work to facilitate the growth and enactment in experience of self-valuation. The lower the sense of self-esteem, the more information, energy and support is needed to refute the believed self-devaluation. The first necessary act is to give "the full attention", to provide the person with the experience that someone "cared for me as a human being, that cared for me as the person I was and for the things that I had to offer". Practitioners need to listen to and care about what is really happening to people, not what helpers **think** is happening, or what others have told them is happening.

One means of facilitating self-esteem is to assist people with self-inventories ("maybe it could be underlined or highlighted") in order to appreciate their strengths, and ways in which to use them. Practitioners can help people to get a sense of control, and to move away from the years of helplessness, desperation, and disorientation, through focussing on one area in which the person could make a change. The resulting feeling of accomplishment will fuel further changes. Focussing on people's abilities, and assisting them to use these abilities in activities from which they can derive meaning, value, and involvement, is supportive of the development of self-esteem.

Another implication for practice which emerged from my experience working with my co-researchers has to do with the intensity of the experience; since the events of the past years are extremely painful to relate and relive, practitioners should consider the effect of asking people to relate their story again and again. How many others, at how many times, have asked? If helpers are not prepared or able to attend fully, and to deal with the results of exploring the experience, contact will not have a helpful effect. Asking people to tell and tell again their histories, without careful processing, can be reinforcing of the despair and pain of the preceding years. If practitioners persist in focussing on what is "wrong", on the painful histories, emotions will emerge in people's reliving of their experience which could be interpreted as "lack of adjustment", or "lability". Perhaps it is more a normal reaction to an abnormal situation.

Practitioners are role models for people involved in adjustment to chronic pain, in terms of their own self-management, self-disclosure, effective communication, genuineness, and problem-solving; helpers have a potent effect, and their presence in the experiencing influences significantly the adjustment process. Practitioners need to do their own work to identify biases, avoidance, hastiness and impatience. It is important for counsellors to develop a mutuality, a relationship of working together; people must take responsibility in their own rehabilitation process, working to create their lives the way they would like them to be. An empathic counselling relationship is important as people strive to integrate and accept their disability, and establish positive ways of living; this is especially important for people with the "invisible" disability of chronic pain upon whose shoulders rests the heavy burden of proof. Belief, based on the person's worth and integrity, is a crucial element in effective helping. How can people trust counsellors who project disbelief? My co-researchers spoke of the many years of feeling on trial, and not being believed that they were experiencing pain; the therapeutic alliance must be based on trust, honesty and belief. These conditions are important so that positive confrontation can be a part of the process.

Practitioners need to give information at all points in the adjustment process, in an open manner. Communication, in the spirit of co-exploration, is extremely important. Explanations, discussion of options, as well as clarity and honesty when the practitioner does not know, are all fundamental. Helpers must work to minimize the "runaround" experienced by people; explanations should be given at each stage, and transitions and connections amongst caregivers should be facilitated. It is important not to be untruthful with people, by telling them, for example, there is nothing wrong with them; nor is it helpful to tell them how they should feel (for example, "don't feel sad"). These tactics are to help the practitioner to feel comfortable.

It is important for helpers to realize the responsibility inherent in the position; even though we can "walk out that door and forget about (them)", they have to live with their situation. Practitioners cannot take away people's power to problem solve and make decisions by unilaterally dictating what they can or cannot handle. Helpers would do well to hasten bureaucratic measures as much as possible by taking control where they can, signing papers, and sending them now. Let the vivid reality of role-reversal operate in practising; if I was that person, would the interaction I am creating with them be helpful? How would I react if I was suddenly sent to see someone else without explanation that I could understand, or if my cheque was held up for weeks?

Helpers can be impatient and ask why hasn't this client thought of other, for example, vocational alternatives before? Counsellors are invited to ask themselves, when this thought emerges, what would they do if they were in a situation in which there were few concrete answers, they were unable to do what they did before, they felt afraid, alone and disoriented in time. LeShan's (1977) discussion of chronic pain has important implications for practitioners in terms of recognizing people's isolation and time disorientation; helpers must focus in the present with people, offer support and understanding to decrease the feelings of lonely isolation, attend to the people and assist them to take control and change that which can be changed.

But with chronic pain there is a real loss of time perspective - we are bound to the immediate **now** of the pain itself. A further aspect of the problem is that chronic pain is experienced in isolation. The French author Alphonse Daudet said, 'Pain is always something new for him who suffers, but banal to those about him. They will all get used to it except myself.' (p. 165)

Practitioners must illuminate the constructive forces which are operating in people's experiencing. They are survivors, still looking for answers. This has been seen as annoying behaviour arising from externalization of control, or a "fix-me" attitude. Looking for

answers can also be considered, however, as an adaptive survival technique, a matter of not giving up, which can be channelled and used by clients to look **look within** for answers, rather than being castigated by helpers for asking. Practitioners must not neglect the positives when problems are being emphasized. Rather than focussing on the hopelessness associated with chronic pain, we must look at the effects of people's environments; the intrinsic worth of people; and resources and forces in the family and in society which are there to be tapped and strengthened to assist in bringing about change.

Strite (1976), staff member in a Californian pain clinic, drew up a list of staff characteristics which is interesting to view in terms of the foregoing implications for practice.

- (1) Faith in the principle of self-regulation and self-responsibility for chronic back pain management.
- (2) Faith that the chronic back 'loser' patient can learn within a relatively short period of time to be an effective manager of his pain.
- (3) Each staff person must have his own personal experiential base with self-regulation, and function as an authentic model for patient interaction.
- (4) That each of the staff persons possesses or at least demonstrates a therapeutic personality ... The cumulative effect of such persons creates an unusually impactful, healing milieu in which the patient has a real opportunity to choose to get well.
- (5) That there be a high level of authenticity, or being your own person.
- (6) There should be a willingness, as well as enthusiasm, for functioning in a non-authoritarian teacher role as opposed to a doctor-patient role in which the doctor dispenses care and the patient passively accepts.
- (7) Finally, the staff, as individuals and as a whole, must recognize their valuable yet limited role in patient recovery. Credit for recovery would always be the patients' who have risked more, shown more courage, and been more creative. After all, it is their life. (p. 5-6)

Although one person cannot change a system, the system is made up of individual persons. Although there were many negative features in their "treatment", each of my co-researchers experienced help from one person which assisted them in their adjustment process with chronic pain. Caregivers can take responsibility for their **own** actions, rather than being determined by their systemic context, in the spirit of being a part of the solution, not of the problem.

Implications for Further Research

The implications arising from this study focus the importance of phenomenological research in understanding human experience. This research contributes to illuminating the meaning of adjustment to chronic pain. This contribution impacts the area of practice, since with greater understanding of experience, we can live our lives and assist others more effectively, as well as the area of theory, since a thorough grounding in existential insight is needed in order to create theories which are true to real experiencing.

This study is a beginning in understanding the actual experience of a phenomenon which has baffled many. It is hoped that more questions will be asked which will facilitate adjustment to chronic pain, and that the "answers" implicit in my co-researchers' experience will be considered.

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